

The Wilmer Macular Degeneration Center

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The Newsletter of the Wilmer Macular Degeneration Center

THE
WILMER EYE
INSTITUTE
AT JOHNS HOPKINS

MACFACTS

Volume 6, Issue 1

February 2004

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The Eye of the Artist

I must have been around nine or ten. I was old enough to walk "up the road" with my best friend Vickie to make my long-awaited purchase. I had saved up one dollar to buy a box of sixty-four Crayola (always the best) crayons complete with a built-in sharpener. I still remember the thrill of all of those beautiful colors, standing at attention, side by side. My artistic soul was stirred. Unfortunately that's as far my artistic ability went- appreciation. I went on to marry an artist and to eventually give birth to an artist. My contribution to art consisted of maternity. Coloring within the lines was the best that I could do.

***"Coloring within the lines
was the best that I could do."***

But recently I have discovered that staying within the lines was the last thing that should have concerned me. Matisse never worried about it. Color was his passion. And passion is the magic ingredient for success in art, in music, in daily life.

Many years ago, I had an opportunity to listen to a lecture given at the meeting of the American Academy of Ophthalmology concerning the visual problems that beset some of the greatest artists of history. I was captivated as the speaker illustrated his lecture with slides of the work of these famous people and discussed the effects that eye disease may have had on the artist, effects that became more obvious over time as the disease progressed.

Continued on page 2 . . .

Look for our next issue in September 2004

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MACFACTS

Directions to the Wilmer Macular Degeneration Support Group Meetings



Johns Hopkins at Green Spring Station is located at the Baltimore Beltway and the Jones Falls Expressway interchange. Take exit 23 B off the Baltimore Beltway and go north on Falls Road to Green Spring Station at the intersection of Falls and Joppa Roads. From the City, drive north on the Jones Falls Exp. (I-83N) to the Beltway (I-695) until the Jones Falls Exp. becomes Falls Road (25). Go ½ mile on Falls and turn right at the 2nd traffic light (Station Drive). Continue to the 4- way stop sign. The Johns Hopkins Pavilions I & II will be directly in front of you. Parking is free and handicapped parking is on the East side of Pavilion I and the South and East sides of Pavilion II. For those using public transportation, the MTA's M10 bus stops on the campus of Green Spring Station.



The Eye of the Artist . . . continued from page 1

Not too long ago, I discovered in the Friedenwald-Romano Library at the Wilmer Institute, a wonderful volume entitled **The Artist and the Eye**, co-authored by James Ravin, that same ophthalmologist whose lecture in 1980 had enthralled me. Drs. James Ravin and Michael Marmor

“Bend the rules or even break the rules. Color outside the lines.”

have collected a series of essays on the critical role that vision plays in the creation of art as well as a detailed account of the ocular tribulations of some of the most famous artists of the past.

Think about how difficult it can be to distinguish between navy blue and black socks. Think about how much easier it is to read when you turn on a bright light. Think about the advances in cataract surgery, in antibiotics, in low vision aids. Although we do not have cures for many of the ophthalmic conditions that we encounter in life, we do have help. The cataract surgery available to Monet was primitive compared to the techniques of today. His frustration with failed surgeries, his anger as he wrestled with post cataract glasses and his joy when he finally was

able to paint to his own satisfaction are vividly detailed in this work. What role did astigmatism play in the work of El Greco? Did you know that Mary Cassat had diabetes and was treated with radium? Did the chronic tear sac infections suffered by Pissaro influence his impressionistic art? Did the medications and treatments prescribed in those early days actually hasten the disease process?

The frustration, grief and sometimes despair of these artists is vividly describe in these essays. Monet’s letters could have been written by any patient whose vision is threatened or compromised. His concerns are universal and timeless. But the driving force, that emotion that enables triumph over adversity is also revealed-passion. The passion of these artists did not allow them to give up. Following rules is anathema to the artistic spirit and they broke the rules whenever necessary in order to continue their passionate pursuit of their life’s work. Without their art a part of them would have died.

So what is the take-away message from this book? Simply put, if you have a passion pursue it. Don’t let physical frailty stop you. If you love to read but no longer can, learn to enjoy talking books and audiocassettes. If your arthritis prohibits you from working in the garden grow your tomato plants in pots on the porch. Bend the rules or even break the rules. Color outside the lines.

--Kitty Sackett, R.N., C.R.N.P.



THE WILMER MACULAR DEGENERATION CENTER Support Group Meeting Schedule

March 2, 2004

Peter Campochiaro, M.D.
The George S. & Delores Dore Eccles Professor of Ophthalmology & Neuroscience
The Johns Hopkins School of Medicine
“The Current Status of AMD Research: Is There Hope for the Future?”

April 6, 2004

Robert Massoff, Ph.D.
Professor of Ophthalmology & Neuroscience
The Johns Hopkins School of Medicine
Director of the Lions Vision Research & Rehabilitation Center
“Potential Treatments for AMD: What is it and What is Promised?”

May 11, 2004

Christine L. Moghimi, M.S., O.T. R
Low Vision occupational therapist
The Lions Low Vision Research & Rehabilitation Center
“Making the Most of your Low Vision Rehabilitation; Attitudes, Adjustments, and Practical Implications”

AGENDA:

6:00 p.m. – 7:00 p.m. – Guest Speaker
7:00 p.m. – 8:00 p.m. – Small Group Discussions

LOCATION:

Johns Hopkins at Green Spring Station
10753 Falls Road, Pavilion II, Room 125 A
Enter through the main doors, take the first left through the coffee shop to the conference room. It is wheel chair accessible.

DIRECTIONS:

I-695 to Exit 23B North, continue on Falls Road to Green Spring Station at the intersection Falls and Joppa Roads. (see map on back cover of this issue)

FREE PARKING

Please call 410-614-6208 to reserve a seat and hear announcements.



Genetic Study of Macular Degenerations

**Do you have macular degeneration?
Do you have a living brother or sister who also has macular degeneration?**

If your answer is yes to **both** of these questions, we are looking for you! The Wilmer Macular Degeneration Center is conducting a study aimed at increasing our understanding of the causes of macular degeneration. We are searching for mutations (mistakes) in genes that contribute to these conditions. A small blood sample and a photograph of the back of the eye is all that is needed from each participant.

If you would like to learn more about the study, please contact the coordinator of the study:

Betsy Campochiaro, R.N., M.S.N.,
Maumenee 207, 600 N. Wolfe
Street, Baltimore, MD 21287
Voice: 410-614-6208
E-mail: bcampo@jhmi.edu

Do you wanna be in the pictures?

It is not too late to become a famous person through the video media. But famous for what..., you make ask. Have we got a deal for you! This is your chance to participate in a worthwhile endeavor that may help other families and patients around the country learn to cope with their diagnosis of AMD. The nurses of the Wilmer Macular Degeneration Center are compiling materials to include in an information packet that will be devoted to the development of AMD support groups. The goal of this project is to provide nurses and other health professionals with the resources and information needed to begin the network of patients helping patients. Programs such as the one at Wilmer, help patients learn about their disease process, adjust to living with low vision and thereby become more independent in activities of daily living. So will you help us spread the news? We are looking for volunteers to be active participants in a small group discussion on living with AMD. This will be a special meeting at Greenspring Station. We will videotape this session in hopes of including it in the support group educational packet for health professionals. If you live too far away to help us, keep in touch. We can send this packet to your eye professional so a group could be started in your area.

To volunteer for this activity please call 410-614-6209.

--Betsy Campochiaro, R.N., M.S.N.



Peter McDonnell, M.D., Assumes Chairmanship of Wilmer

Peter John McDonnell, M.D., an ophthalmologist known for his expertise in diseases of the cornea and refractive surgery, is the new director of the Wilmer Eye Institute at Johns Hopkins.

A 1982 graduate of the Johns Hopkins University School of Medicine, Dr. McDonnell was chairman of the ophthalmology department at the University of California-Irvine from 1999 to July of 2003. He was the first physician to use excimer ("cool") lasers in the treatment of astigmatism in the 1990s.

McDonnell's research interests include surgical correction of refractive error, gene therapy for corneal wound healing and inflammation of the cornea. He has been awarded large research grants from the National Eye Institute for his studies of cataract surgery, corneal transplantation, viral diseases of the eye and laser surgeries, among other topics, and has published more than 200 journal articles on his work. McDonnell also holds four patents, two in laser surgery techniques.

Dr. McDonnell asked us to include the following: "Greetings to the readers of MacFacts! As the new Director of Wilmer, I could not be more proud of the dedicated physicians, nurses and staff at Wilmer who are focused on caring for our patients with macular degeneration and discovering the causes and more effective treatments for



Dr. Peter J. McDonnell, M.D.

"Wilmer has many areas of expertise but none more impressive that our program in macular degeneration."

this dreaded condition. Wilmer has many areas of expertise, but none more impressive than our program in macular degeneration."

The Macular Degeneration Center will surely benefit from Dr. McDonnell's skill and talent as an outstanding ophthalmic surgeon, physician, teacher, researcher and administrator. His high standards of patient care and research into eye disease ensure that the goals of the Macular Degeneration Center will continue to be met with his support and enthusiasm. Welcome Dr. McDonnell!

--Betsy Campochiaro, R.N., M.S.N.



Emotional Fallout of Vision Loss

I received this poem from a patient who has eloquently channeled his pain from vision loss into the written word. He accurately describes the sense of shock, loss and depression that often comes when sight is compromised. Although he did not have macular degeneration and he eventually regained his sight, this poem serves to caution family members of the dramatic and devastating consequences of sight loss. This loss can often cause mood changes, and while the majority of individuals recover and adjust over time, a good number continue to suffer a recognizable and treatable depression. Neither the aging person nor their family should accept this as part of the mood of the elderly. Read on, raise your the level of awareness of treatable side effects of vision loss and if your loved one is suffering, seek help. --Betsy Campochiaro, R.N., M.S.N.

Sighted, Sightless and Back Again By Ruby Plushner

*Have you had a bad day? Or perhaps so you say,
Well my friends let me give you a clue.
No matter how bad are the things that you feel
There is someone who's worse off than you.
I'll speak of myself while I tell you this tale,
A tale about eternal night,
How it feels, what it does to your mind
When you find, that you suddenly
Have lost your sight.
If you cannot see, - as it happened to me
It puts you in a terrible rut.
Because when you arise and you open your eyes
It's the same as if you kept them shut.
Imagine a world where a whippoorwill sings
As it sits on a tree or a hill
With no color, no movement, no flutter of wings
As it gives forth a delicate trill.
The sounds of the waves as they break on the shore
You've a sense of great power and motion.
You can sit and feel the sun as it sets.
Touch a wave, but you can't see the ocean.
I can feel the warmth of my wife's embrace
But the thing that I really seek
Is to gaze upon her lovely face,
To see a tear upon her cheek.
If there were one advantage, I guess that it would be
Is that you would stay forever young
You wouldn't age for me. But now that I've recovered
There's just one thing to tell, I'm glad to see you once again—
For I have been through hell.*

For more information on depression in the elderly please refer to:

Living Longer Depression Free: A Family Guide to Recognizing, Treating, and Preventing Depression in Later Life [LARGE PRINT] by Mark D. Miller, Charles F. Reynolds, Barry D. Lebowitz
Paperback: 288 pages; Dimensions (in inches): 0.63 x 9.36 x 6.16 **Publisher:** Johns Hopkins Univ Pr; Large Print edition (May 1, 2003) **ISBN:** 0801871697



Resource Tips

Blind Industries and Services of Maryland

2901 Strickland Street
Baltimore, MD 21223-2796
410-233-4567, 1-888-322-4567
www.bism.com

The Blind Industries and Services of Maryland focuses on rehabilitation services, training and employment opportunities to Maryland citizens who are blind or visually impaired. The following programs are for seniors with low vision or who are blind:

Home Teaching -- This program provides in-home instruction in non-visual techniques to seniors and others who are blind and unable to attend a full-time, rehabilitation training program.

Senior Encounter -- A weeklong, on-site program for adults 55+ who are blind or visually impaired, Senior Encounter promotes socialization with peers in a supportive atmosphere that encourages open communication, discussion and learning. Participants are taught valuable, non-visual techniques for cooking, light meal preparation, Braille, communication and computer technology. A special focus is put on independent travel and

community outings to such places are shopping malls and restaurants for exercise, fun and enjoyment. Seniors also enjoy making arts and crafts, gardening, woodworking and more.

Senior Support Groups -- Join a monthly two-hour support group where you can make friends and discuss common issues about dealing with vision loss. Often held over lunch, our seniors enjoy guest speakers, learn valuable skills and socialize in a dynamic environment that promotes overall well being.

SAIL -- Seniors Achieving Independent Living - This unique year-round program for blind and visually impaired adults 55 and over includes discussion groups, social activities, skills training and lunch. This full-day program meets every Tuesday and Thursday from 9:30 a.m. until 3:30 p.m. at the Charity Community Church of God in Baltimore.

ClinicalTrials.gov

This web site provides regularly updated information about federally and privately supported clinical research in human volunteers. Just type in "macular degeneration" into the search box and all the current trials will be displayed. Other information can be obtained from this site such as; what are clinical trials, search engines for reliable health information, and information on genes and genetic conditions. On the web at www.clinicaltrials.gov



Tax Season Is Upon Us!

Financial implications for legally blind status

Social Security Disability Insurance (SSDI)

--Visually handicapped individuals may be eligible for Social security benefits. Benefits are based on how much a worker has paid into the Social Security fund through payroll deduction not on financial need. Family income and assets are not counted in determining the benefits. After receiving disability for 2 years, a disabled person will also be protected under Medicare, the Federal health insurance program.

Supplemental Security income (SSI)

--People who are disabled (legally blind) with little or no regular income, savings or assets may be eligible for a monthly check. Financial need is considered in determining eligibility benefits. Benefits may be received even if the person has never worked. In most states, people who are receiving SSI are also eligible to receive Medical Assistance (Medicaid).

For more information on both of the above programs, contact the Social Security Administration in MD: 1-800-772-1213 or The National Federation of the Blind: 410-659-9314.

Tax exemptions-- Any legally blind taxpayer may obtain an extra exemption on both state and federal tax returns. This means that a person's gross income is reduced by the amount of the exemption when calculating taxes. When submitting a tax return, attach a

copy of a letter from your doctor stating that one is legally blind. Contact the Internal Revenue Service: 800-829-1040.

Property Tax--In many states any legally blind person who owns and resides in his or her home as well as the surviving spouse of a legally blind resident may qualify for a reduction of the assessed value of the real estate. A certain amount of the assessed value is disregarded when calculating the property tax. Contact the your State Department of Assessment and Taxation; for Maryland: 410-767-1191. -- Jim Deremeick

MacFACTS

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<http://www.wilmereyeinstitute.net/mdp/mdp.html>.

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Baltimore, MD 21287-9228

Email: mdc@jhmi.edu

General information & referrals:
410-955-5080



Research Update

A New Study with Photodynamic Therapy



As we have reported previously in this newsletter, photodynamic therapy (PDT) with verteporfin (VISUDYNE) has been shown to reduce the risk of additional vision loss beyond what a patient has on presentation to an ophthalmologist in some patients with wet age-related macular degeneration (AMD) (abnormal blood vessels and scar tissue that can grow in the center of the retina, the light-sensitive tissue that lines the back of the eye).

PDT is a two-step treatment, which involves the intravenous administration of a drug, verteporfin. The verteporfin by itself is inactive, but it collects in the abnormal blood vessels in wet AMD. Exposure to a red laser light that does not produce any heat to burn the retina, can activate the verteporfin and lead to the closure of these abnormal blood vessels. Frequently, additional courses of treatment are needed as often as every three months until the situation stabilizes. In the studies performed so far, patients have had to be treated on average 5-6 times over a two-year period.

In some patients with abnormal blood vessels in the retina that appear on special photographs in a pattern termed "minimally classic," there is no treatment that has been proven to be beneficial. Some studies have suggested that PDT with verteporfin may reduce the risk of vision loss in minimally classic cases,

other studies have suggested that PDT with verteporfin does not reduce the risk of vision loss in minimally classic cases. To try to determine which conclusion is correct, a new clinical study called the **VMC (Visudyne in Minimally Classic CNV Secondary to AMD) Trial** at the Wilmer Eye Institute and at a number of other participating centers in North America and Europe, is underway. This study will evaluate whether PDT may be of benefit to a certain group of patients who have developed "minimally classic" pattern of wet AMD before it has become too large or before too much vision has been lost. If you would like more information on this study, please contact the sponsoring drug company, QLT, for the name of an ophthalmologist and eye center closest to you that likely is participating in the study, at 1-866-944-3344 or the coordinator for the study at the Wilmer Retinal Vascular Center, Pat Nesbitt, R.N., 410-955-2965.

--Neil M. Bressler, M.D.
The James P. Gills Professor of Ophthalmology
Chair, VMC Trial

Important News!!

Medicare announced on January 29, 2004, that PDT will be covered for most patterns of abnormal blood vessel growth for wet macular degeneration. The patterns now covered by Medicare are both the "classic" and the "occult" types. Medicare covered classic patterns in the past and now will cover the occult type. While this news may take a few months to be instituted throughout the country, if PDT is indicated by your doctor, Medicare likely will cover it.



Research Update

A New Trap Is Set for Wet AMD



A clinical research trial is starting in February of 2004 to investigate a new drug for wet AMD. The trial will examine the effects of VEGF-Trap, an agent that traps VEGF (vascular endothelial growth factor) and prevents it from binding to its receptor, which is necessary for it to stimulate leakiness of blood vessels and growth of new vessels. VEGF is a major cause of abnormal blood vessel growth and leakiness that occurs in wet AMD, so there is reason to think that VEGF-Trap may help. In animal models of abnormal blood vessel growth under the retina, like that which occurs in wet AMD, VEGF-Trap was effective and well tolerated. This is the impetus for the clinical trial, which is primarily a safety trial, but will also look for signs of effectiveness.

There are 2 other anti-VEGF treatments that are being tested in clinical trials, Macugen and Lucentis. They are given by injections directly into the eye. VEGF-Trap is given by injection into a blood vessel in the arm. This is a less invasive approach and allows treatment of both eyes at once. These are some of the most commonly asked questions regarding the VEGF-Trap study.

1) If I participate in this trial, will I be sure to get VEGF-Trap?

In order to determine if VEGF-Trap

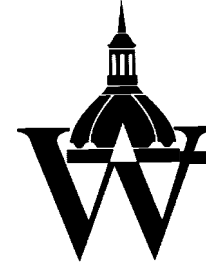
has a beneficial effect, it is necessary to compare patients who receive VEGF-Trap to those that do not. If you enter the trial, you will be randomized to receive VEGF-Trap or a placebo; the ratio of VEGF-Trap to placebo is 3:1 (3 patients will be assigned to VEGF-Trap for every 1 patient assigned to placebo). However, at the end of the test period, if you received placebo, you will be given the opportunity to receive VEGF-Trap.

2) I have had wet AMD for several years in one of my eyes and it has resulted in severe limitation of vision in that eye. Is it possible for VEGF-Trap to restore vision in that eye?

When abnormal blood vessels are under the retina for a long time, they stimulate scarring which leads to permanent loss of central vision. Once this has occurred, even an effective treatment for abnormal blood vessels cannot restore vision. So if you have had wet AMD in one or both eyes for several years and it has resulted in severe loss of vision, VEGF-Trap is unlikely to help.

3) My doctor told me that I have the type of blood vessels under my retina that is not helped by photodynamic therapy. He has told me that there is no proven effective treatment for me and has recommended no treatment. My vision has gradually been getting worse. Would it be possible for me to enter the VEGF-Trap trial?

Yes, you are eligible for the VEGF-



Trap trial provided you meet all of the other eligibility criteria.

4) I am receiving photodynamic therapy for wet AMD. Can I be considered for VEGF-Trap?

Photodynamic therapy has been demonstrated to slow the rate of vision loss due to wet AMD. That is more than what we know about VEGF-Trap at this point. It is unwise to trade a known for an unknown. Therefore, if you are receiving photodynamic therapy, we recommend that you stick with it.

5) I think I may be eligible for the VEGF-Trap trial and I am interested in being considered. I don't live in Baltimore, but I am able to travel to Baltimore once a month. What can I do to be considered for the trial?

To be considered for the trial, it is necessary to have a screening exam to make sure you meet all the eligibility criteria. That visit also provides an opportunity for the doctors to give you detailed information about VEGF-Trap so that you can make an informed decision as to whether you would like to participate or not. If you are from the Baltimore area, it is fine to just call and make an appointment for a screening visit. However, if you are not from the Baltimore area, we would like to maximize the chance that you are eligible before you make a trip. To do this, you should request that your doctor send a copy of your records and a recent fluorescein angiogram. We will evaluate

this information and determine how likely it is that you are eligible. Once you have that information, you can better decide if it is worthwhile to make the trip or not.

6) If I enter the trial and receive VEGF-Trap and it helps me, what happens at the end of the trial? Will I have to go back to receiving no treatment and just hope for the best?

No, if you receive VEGF-Trap in the trial and there is objective evidence that you have improved during the trial, you will be eligible to continue to receive VEGF-Trap. Of course neither you nor your doctors will know whether you are receiving VEGF-Trap until the end of the trial when the code is broken. If it turns out that you were not receiving VEGF-Trap and you have not improved on your own during the trial, you will also be eligible to receive VEGF-Trap. So every patient who enters the trial will be able to receive VEGF-Trap at some point, unless that patient improves on his/her own, in which case there would be no need for it anyway.

Let's hope that this clinical trial provides a first step toward providing new weapons to help hunt down and trap wet AMD. If you have any other questions regarding this VEGF-Trap study, please contact the coordinators for the study, Gulnar Hafiz or Beth Van Anden at (410-502-5987).

--Quan Dong Nguyen, M.D.
Peter Campochiaro, M.D.

Principal Investigators for VEGF Clinical Trial